

RESOLUTION 86-10A

Title: Stillbirth Awareness. Adopted as Amended.

Introduced by: Domenic R. Federico, MD, for the Kent County Delegation

Author: Donald P. Condit, MD, MBA

RESOLVED: That MSMS encourage the next annual Conference on Maternal & Perinatal Health Committee to maintain all efforts to increase stillbirth awareness and to comply with current recommendations among Michigan health care providers of this tragic pregnancy complication; and be it further

RESOLVED: That the Michigan Delegation to the AMA ask the AMA to lobby Congress to enact H.R. 521 the Stillbirth Awareness and Research Act of 2009, which is a federal resolution that promotes stillbirth research by standardizing the definition of stillbirth and funding a national repository for stillbirth data, authorizes a campaign to increase public awareness of the risk for stillbirth, and encourages the director of the National Institutes of Health to allocate more resources to stillbirth research.

RATIONALE: The first resolved was amended to allow the Maternal and Perinatal Health Planning Committee the option of selecting the best educational approach(es) to increase awareness of stillbirths at the next annual Conference.

District 77 - HR 102

From: "Federico Mariona" <fmariona@att.net>
To: <Kevingreen@house.mi.gov>
Date: 4/30/2010 12:24 PM
Subject: HR 102
CC: <SenTGeorge@senate.michigan.gov>

Representative Green.

This is written to support your efforts through the above resolution adopted by the House on June 25, 2009. The birth of a death fetus is one of the most common adverse (and tragic) pregnancy events. Fetal death is defined by the United States National Center for Health Statistics. I am certain you are aware that there is no world-wide standard definition. Parents' groups preferred the term "stillbirth".

The American College of Obstetricians and Gynecologists (ACOG) installed a number of years ago the Fetal Infant Mortality review Projects (FIMR) for the purpose of understanding the events that place the pregnant women at risk for such event, appropriate identification of preventing factors and a scientific approach to the study of each fetal death. As of recent, ACOG published an extensive updated "practice bulletin" addressing management of stillbirth (ACOG # 102, March 2009).

In Michigan, specifically, the fetal and infant mortality review process has two objectives: 1 describe significant social, economic, cultural, safety, health and systems factors that contribute to this mortality and 2, design and implement community based action plans founded on the most accurate information obtained from the reviews. Kent County is one of a number of Michigan counties that has a functional FIMR team for the last 8 years. Their 2009 report shows that 280 infant deaths were reviewed by the FIMR team, also demonstrating still a clear discordancy between ethnic groups. 58% of the deaths were determined to have been caused by "perinatal conditions". **Thereby the emphasis is on the provider of obstetrical care** (obstetrician, family physician, midwife) **to be an involved and integral part of the efforts to reduce this event that afflicts one in 160 pregnant women.** The obstetrical provider must be an active partner in obtaining all the appropriate studies on the stillborn, including the afterbirth (placenta). It is the role of the attending physician to communicate all the obtained reports and offer support on a timely manner. The second largest number of such losses in Kent county (second to early preivable losses) occurred between weeks 37 and 40 weeks of gestation, affecting women with chronic conditions, maternal age past 36 and more. Michigan budgetary constraints put limits to these investigations and the maximum effort of the teams has been placed on infant deaths, less on stillborns where the physician's intervention is extremely important at the time of the adverse event.

The Maternal and Perinatal Health Care Committee of the Michigan State Medical Society holds an annual conference for the purpose of presenting to interested providers of obstetrical-neonatal care issues that are relevant for the daily practice. In addition, the conference includes a yearly discussion of the Michigan "report card" for activities towards improving obstetrical care. On March 24, 2010 at our last meeting, the activities of the FIMR teams around the state were reported, along with the recent changes and significant budget cuts that will impact care and as a result will impact outcomes.

On its most recent publication the Global report on preterm births and stillbirth along with the global alliance to prevent prematurity and stillbirth **emphasizes the need to mobilize the public attention** to achieve a multidisciplinary approach to this complex problem.

Tracking HR 521, the Lautenberg legislation, shows no recent meaningful activity. The practice of medicine is mostly based on local or regional efforts to improve outcomes. The Michigan legislature may be instrumental in protecting the level of funding to relevant programs to provide appropriate services to the pregnant women of Michigan.

We are prepared to provide you and your colleagues with relevant information to support your efforts.

Sincerely,

Federico G. Mariona, MD. FACOG. FACS
Chairman
Maternal Perinatal Health Care Committee
Michigan State Medical Society

Reps. Green, Horn, Hildenbrand, Walsh, Meekhof, Byrum, Haines, Moss, Denby, Lund, Lori, Kurtz, Daley, DeShazor, Rocca, Corriveau, Hansen, Terry Brown, Lindberg, Elsenheimer, Mayes, Bennett, Lemmons, Young, Geiss, Simpson, Genetski, Opsommer, Pearce, Dean, Espinoza, Lahti, Nerat, McMillin, Schuitmaker, Angerer, Meadows, Valentine, Roy Schmidt, Bauer, Stanley, Bledsoe, Durhal, Miller, Huckleberry, Kennedy, Marleau, Liss, Haase, Constan, Barnett, Scripps, Robert Jones, Coulouris, Griffin, Tlaib, Wayne Schmidt, Agema, Booher, Knollenberg, Rogers, Kowall, Paul Scott, Ball, Proos, Spade, Neumann, Stamas, Tyler, Caul, Crawford, Bolger, Haveman, Moore, Pavlov, Meltzer, Rick Jones, Sheltroun, Leland, Smith, Slavens, Roberts, Slezak, Haugh, Jackson and Cushingberry offered the following resolution:

House Resolution No. 102.

A resolution to memorialize the United States Congress to enact H.R. 521, the Stillbirth Awareness and Research Act of 2009.

Whereas, Each year approximately one in every 160 pregnancies in the United States ends in stillbirth. Stillbirth is the term health care providers use to describe the unplanned loss of a fetus due to natural causes late in the pregnancy. Stillbirths are quite different than miscarriages. A miscarriage often occurs during the first-trimester, whereas a stillbirth takes place during the third-trimester. Carrying the fetus until the third-trimester gives a greater chance for the fetus to live even if delivered prematurely. In at least half of all cases, physicians can find no cause for the pregnancy loss. **In some cases of stillbirth, the mother may notice a decrease in fetal movement or a decrease in kicking of a fetus toward the end of the pregnancy.** Many stillbirth mothers are young, in good health, and had used good prenatal care practices throughout the pregnancy. In 15 percent of cases, stillbirths happen during delivery and labor, devastating parents who had expected to deliver a healthy baby; and

Whereas, Despite the relatively high incidence of stillbirths yearly in the United States, scant research into the causes of this heartbreaking loss of pregnancy is performed. The United States Centers for Disease Control and Prevention (CDC) collects data on stillbirths, but the data is incomplete and inconsistent. In many cases, the federal government, state governments, local governments, and health care providers all use a different definition of stillbirth. Comprehensive research into the causes and prevention of stillbirth are impossible without a nationally accepted definition of stillbirth and a standardized data collection protocol; and

Whereas, H.R. 521, the Stillbirth Awareness and Research Act of 2009, would promote stillbirth research by standardizing the definition of stillbirth and creating a national repository for stillbirth data. H.R. 521 would also authorize a campaign to increase public awareness of the risks for stillbirth and encourage the Director of the National Institutes of Health to allocate more resources to stillbirth research. The bill would also promote state legislation allowing the issuance of a Certificate of Birth Resulting in Stillbirth, as opposed to the more standard practice of issuing only a death certificate in the case of a stillbirth. Clearly, the parents and babies who have gone through this traumatic experience at least deserve this acknowledgment; now, therefore, be it

Resolved by the House of Representatives, That we memorialize the United States Congress to enact H.R. 521, the Stillbirth Awareness and Research Act of 2009; and be it further

Resolved, That copies of this resolution be transmitted to the President of the United States Senate, the Speaker of the United States House of Representatives, and the members of the Michigan congressional delegation.

Alive and Kicking

NICK HYTREK
Sioux City Journal
September 11, 2008



(Staff photo by Tim Hynds)

Jennifer McCune holds her baby, Danny, who was born by emergency c-section after McCune noticed he wasn't kicking as he had been.

Last November, Jennifer McCune noticed a magazine story recommending that pregnant women monitor the kicks and movements of their unborn babies.

Little did she know that article would quite likely save her own baby's life a month later.

Due to give birth in December, the South Sioux City woman took the article's advice and each evening spent an hour counting her baby's kicks. On Dec. 6, McCune, who was 37 weeks pregnant, noticed her baby wasn't moving as much. She counted only one kick during an hour that evening.

"At that point I called my doctor to see what I should do. She said to come in immediately," McCune said.

At St. Luke's Regional Medical Center, doctors hooked McCune to a monitor and discovered the umbilical cord had wrapped around the baby's neck four times. Just three hours after feeling only one kick, McCune gave birth via cesarean section to Danny, a healthy baby boy.

McCune's attention to Danny's movements meant the difference between life and death.

"I was scheduled for a C-section on the 14th (of December). They said he wouldn't have made it that long," McCune said.

It's stories like McCune's that women refer to when promoting Count the Kicks, a campaign that encourages women to track fetal kicks and movements during the third trimester of pregnancy. Reduced fetal movement can be a sign of trouble, and acting on that inactivity can reduce the incidence of stillbirths or other health problems, said Kim Piper, state genetics coordinator with the Iowa Department of Public Health and a Count the Kicks spokeswoman.

"There are studies that show a significant decrease of fetal movement is a sign of fetal distress," Piper said.

For Janet Petersen, the cause is personal. An Iowa state representative in Des Moines, Petersen had a daughter, Grace, who was stillborn five years ago. During delivery, doctors discovered a knot in the umbilical cord.

During a conversation with her minister while she was still in the hospital, Petersen learned that another woman from her church had a stillborn child just months earlier. That woman, Tiffan Yamen, and Petersen decided to do something so that other families might be spared the tragedy.

"No family should have to go through a healthy pregnancy and lose a healthy baby," Petersen said.

Through word of mouth, the two joined forces with nearly 30 other families who had experienced a stillbirth. Naming themselves Healthy Birth Day, they set out to find a way to let women know they could play a role in ensuring a healthy, live birth for their baby.

The Iowa Department of Public Health was able to secure some legislative funding for stillbirth prevention, and the group decided to promote kick counting, which Petersen had learned about from a public health campaign in Norway.

It would be a simple way for women to keep tabs on their babies' health.

"It's a great way to bond with the baby for mom and dad and for brothers and sisters. It's free and easy and available to everyone," Petersen said.

Through Teresa Heinz Kerry, wife of 2004 presidential candidate Sen. John Kerry, the group received a Heinz Family Foundations grant to pay for public service announcements. Those PSAs, featuring Iowa first lady Mari Culver and Iowa football coach Kirk Ferentz, have aired on Iowa radio for the past year. Similar PSAs are airing in Pennsylvania. The group hopes those ads are just the beginning.

"We're hoping to take this message into larger states and get the word out. We really want to expand this message," Piper said.

The group is working on brochures, posters and other literature they hope to make available to all Iowa doctors and other providers.

"We're trying to get every physician to tell every pregnant woman," Piper said.

Petersen said it's a message that many women haven't heard.

"Most women think if you've made it through the first three months, you're home free. The last trimester, you need to pay attention," she said. "My doctor never talked to me about counting the kicks."

McCune said that during both of her pregnancies, her doctor spoke with her about paying attention to her baby's activity level. But she never really understood why it was important and didn't realize that she needed to pay attention to more than just kicks. Now she plans to help inform other women about kick counting.

"It's a hard thing to talk to pregnant moms about," she said. "It's really normal when you're pregnant to have many fears. I don't want to scare them."

But a little scare is worth it, McCune said, when doing something so simple helped save her son's life.

"He's healthy and perfect," McCune said. Alive and kicking.

Stillbirth can be prevented in many cases if women are told the early warning signs. Typically, a decrease or increase (hyper-activity) in fetal activity is a signal that your baby is in distress. monitoring such activity by "Kicks Counting" is a no cost low tech way to heighten your awareness.

Letters of Support

Janet Petersen
STATE REPRESENTATIVE
Sixty-Fourth District
Statehouse: (515) 281-3221
e-mail - janet.petersen@legis.state.ia.us

HOME ADDRESS
4300 Beaver Hills Drive
Des Moines, Iowa 50310



House of Representatives
State of Iowa
Eighty-Second General Assembly
STATEHOUSE
Des Moines, Iowa 50319

COMMITTEES

Commerce, *Chair*
Human Resources
Ways & Means

May 6, 2010

The Honorable Kevin Green
State Representative
PO Box 30014
Lansing, MI 48909

Dear Rep. Green,

Thank you for your legislative work to help prevent stillbirths in Michigan. My husband and I also know the heartache of losing a daughter to stillbirth. Our daughter, Grace Elizabeth died of a true knot in her umbilical cord when I was nine months pregnant after a healthy and otherwise uneventful pregnancy.

I was shocked to learn that one out of every 150 pregnancies ends in stillbirth, claiming 26,000 lives in the United States each year. Stillbirth is one of the most common pregnancy complications, yet one of the least talked about or researched maternal health issues in our country.

A few years ago, we learned that Norway cut its preventable stillbirth rate by 1/3 through a research study that educated expectant parents about the importance of tracking fetal movement daily during the last trimester of pregnancy. We decided to launch a *Count the Kicks* campaign in Iowa with the goal of achieving the same success as Norway in saving babies' lives. The campaign enlisted the help of maternal health care providers and Iowans to ensure expectant parents were educated on the importance of monitoring their babies' movements daily during the third trimester.

Many maternal health care providers consider it a standard of care to educate women about kick counting, yet we learned women in Iowa were not receiving the educational information they needed to understand how or why they should *Count the Kicks*.

Since the campaign's official launch in 2009, more than 56% of Iowa's birthing hospitals and 55% of Iowa's known OB/GYN clinics have begun participating in the campaign. We have living proof the campaign is saving lives as you will see from the testimonials I sent you. Unfortunately, as a voluntary program, we still do not have a 100% participation rate from Iowa's maternal health care providers, so we know not all expectant parents are receiving our lifesaving educational materials. We recently received a grant from the March of Dimes Iowa Chapter to expand our *Count the Kicks* outreach efforts to more members of the maternal health community. We are looking forward to reaching more expectant parents with their help.

We continue to receive very positive feedback from both the medical community and expectant parents about *Count the Kicks*. Nurses tell us they now finally have educational materials to provide expectant parents on the #1 call they receive – questions about fetal movement and kick counting. Many parents tell us this is the first time they have ever received information on how to actually *Count the Kicks* instead of just being asked, "Is your baby moving okay?"

I wish I had known how to *Count the Kicks* when I was pregnant with Grace. While I will never know if it would have saved her life, I do know it has saved other babies' lives. I commend you for your efforts to draw more attention to the issue of stillbirth in Michigan and prevent other families from enduring the heartache we both know all too well.

Sincerely,

A handwritten signature in cursive script that reads "Janet Petersen".

Janet Petersen



*Hundreds of Police Chiefs, Sheriffs,
Prosecutors, other Law Enforcement
Leaders, and Violence Survivors
Preventing Crime and Violence*

May 6, 2010

Honorable Kevin Green
Minority Caucus Whip
State Capitol
Lansing, MI 48909

Dear Rep. Green,

Thank you for your leadership to ensure that parents have exposure through their obstetrician to adequate prenatal information on the development of their child and the risk of stillbirth. It is a natural request that should not be overlooked.

Not only is the potential for and signs of stillbirth taught to obstetricians, biomedical technological advances also suggest proven methods of identification and best practices for professionals to achieve successful outcomes. By having the knowledge, it is appropriate that it be shared. The patient holds the physician in esteem and is counting on them to give the parents the benefit of the acquired knowledge.

Knowledge is an extremely powerful preventative measure. Just as parents who received information in New York hospitals were shown to reduce the levels of shaken baby syndrome (Dias, Smith, DeGuchery, Mazur, Li & Shaffer, 2005), so, too, can adequate and timely information help mitigate the negative implications of stillbirths.

Adequate prenatal education and care provided to parents can help in many ways to support the successful outcomes for newborns and their long-term development.

Best regards,

Kathy G. Pelleran
State Director



April 30, 2010

Brandy Nash
Chief of Staff
Rep. Kevin Green
kevingreen@house.mi.gov

Dear Representative Green;

First please allow us to extend our deepest condolences for your loss. As you know, the loss of a dearly wanted and loved child compares to no other. We lost our first son, Garrett, on July 31, 2004 to an umbilical cord accident. I am a pediatric nurse practitioner and was horrified at the lack of information provided to me as a mother-to-be but also as a trained medical professional regarding stillbirth and the things I could have been doing to at least identify the risks.

Each year 30,000 families in the United States experience the excitement and wonder of a pregnancy while planning for a greatly anticipated birth. Devastatingly, in the final days before delivery these same 30,000 families have to will endure their precious baby being stillborn. For most, the cause is never known. We, at The Star Legacy Foundation, believe these are preventable tragedies.

The Star Legacy Foundation was started by family and friends of Garrett Jamison Wimmer, stillborn on July 31, 2004. Our focus is to raise funding and awareness so better technology, education, research, and support are available to families and health care providers.

The purpose of our letter today is to support your pending legislation which would require healthcare providers to provide information regarding kick counting to their patients between they 20th and 28th weeks of pregnancy.

Please let us know how we can support your efforts for this very important cause..

We thank you in advance for your very important efforts.

Sincerely,

For the Star Legacy Foundation

Lindsey Wimmer, BSN, MSN, CPNP

Stillbirth Mom and Co-Founder

Lindsey@starlegacyfoundation.org

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FirstCandle

HELPING BABIES SURVIVE & THRIVE

April 29, 2010

Representative Kevin Green
State of Michigan
Anderson House Office Building N 1096
Lansing, Michigan 48933

Dear Representative Green:

I am pleased to send this letter of support and appreciation for your leadership in advancing legislation in the arena of stillbirth. Your expertise and efforts to author bills that urge national funding of research, and statewide education and awareness of stillbirth is remarkable. I truly believe that Michigan has the opportunity to lead the nation in implementation of initiatives that will significantly increase infant survival.

By way of background, First Candle is a national nonprofit organization with 40 years history, dedicated to getting every baby to a healthy first birthday...and many beyond. We were founded by parents and scientists, and known for many decades under the name National SIDS Alliance. In 1994 we joined with the American Academy of Pediatrics and others to launch the "Back to Sleep" campaign, which by teaching families to place babies on their backs for sleep has reduced the incidence of death by almost 50 percent over the past decade and saved the lives of an estimated 30,000 infants. We have also worked to advance research in the field by funding projects and advocating for research at NIH to solve the mystery of SIDS.

Now we have the opportunity to do the same for stillbirth, which is ten times more prevalent than SIDS. In 2003 the First Candle Board of Directors made a bold decision to broaden the organizational mission and change the name to reflect our expansion into stillbirth and other infant death, as well as to enhance our public health prevention initiatives. A key campaign that we are currently undertaking involves teaching parents and professionals across the country about the life saving potential of "kick counting", or monitoring babies' movements during the last trimester of pregnancy. We know the potential of parents and education, and we know all too well the pain of losing an infant prior to birth. This happens far too often. Given the statistics of 70 babies per day in our country being stillborn, this affects every state, every city, every neighborhood, and most extended families at some point.

I urge the attention and support of your colleagues for House Bill 6091 that will have health care providers notify *all expectant mothers*, verbally and through written information, about the risk of stillbirth and preventative measures that can be taken, including kick counting. It

is through this uniform and comprehensive educational outreach that we will finally be able to make advances in reducing the number of stillborn babies.

Please convey this important information to your colleagues and put Michigan in the forefront of states that reduce the number of stillbirth and other unexpected infant deaths during the decade ahead.

Sincere thanks,

Marian Sokol

Marian Sokol, Ph.D., MPH
President, First Candle/SIDS Alliance
1314 Bedford Avenue
Baltimore, Maryland 21208
800-221-7437
www.firstcandle.org

Dear Rep. Marc Corriveau and Members of the House Health Policy Committee,

I am writing to you in support of the House Bill # 6091.

I am a bereaved parent of a 38 week baby boy named Charlie. Like so many other parents across our state my son was stillborn even though we had excellent prenatal care. Looking back after his death I now know more about what to look out for to reduce the risk of SADS, unfortunately I was never given this information by my OBGYN. I strongly believe that having my doctor speak with me about Stillbirth and Fetal Movements could have helped us bring home our healthy 6 lb 9 oz baby boy. I am distressed to think that most OBGYN's do not discuss this with patients to give them the knowledge they need to take care of themselves and their unborn children.

Two days before my son's death I felt violent kicking but did not know that I should call or go in. I had felt decreased movement for a week prior but was not told to do kick counts. I had no idea that babies can die right before they are meant to be born. I feel like this is a huge educational opportunity for Doctors, patients need to have all of the information so they are not left wondering like me, if they could have saved their child. Knowledge is power..I was powerless.

There is a curtain around Stillbirth and the families affected by the sorrow it leaves behind. There is a stigma associated with Stillbirth and often Doctors want to hide it or touch over it lightly as it might scare patients. I can tell you as a parent of 3 living children that in the hospital after delivery your doctor gives you all of the alarming terrifying statistics on SIDS. I am shocked that they cannot do the same before your baby is born to raise awareness of SADS.

Thank you for your time. Your work will lower the Stillbirth rates in the State of Michigan and will save many families from a lifetime of sorrow.

Knowledge is power!

Sincerely,

Brenda Pratt





Sudden Antenatal Death Syndrome

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Jeanne Johnson - WY

The National Stillbirth Society Inc.

"Because all our Children Matter"

"If I only knew then what I know now....."

Knowledge is a powerful tool; some say the most powerful tool in preparing us to deal with life's experiences. We acquire knowledge from our parents, our peers, our teachers and our observations. One bit of knowledge that expectant mothers need but are rarely given by their doctors is that 30,000 babies will die this year before birth in the U.S. alone, most of them in late term. It's an epidemic that is all but swept under the sheets by the medical community. That is unfortunate because there is information they can convey to expectant mothers that will drastically lessen the chance of a woman suffering a stillbirth.

The leading cause of stillbirth involves an obstruction of the umbilical cord. Like an astronaut's tether linking him to the mother ship during a space walk, the umbilical cord links mother and child until the child she is carrying is born and able to draw in its own oxygen. This cord is prone to entanglements, loops, knots, twists and simple compressions, all of which restrict the flow of life giving blood. All cord issues have a common "signature" that can be identified before its too late.

The "signature" is decelerations in the fetal heart rate, manifested most commonly in reduced fetal activity. Educating women to be on the lookout for this phenomenon is the key to reducing the incidence of stillbirth. Remember, these are otherwise sound and healthy babies whose life is lost for a mechanical reason; a "crimp" in the hose!

If we only knew then what we know now..... my wife and I would be celebrating this Mothers Day 2010 by going out to eat with our 10-year old daughter Camille. A simple cord compression a decade ago denied us that opportunity. Instead, I am spending this Mothers Day writing to urge Michigan Legislators to enact HB6091 introduced by Representative Kevin Green. It's a simple and straightforward Bill that we endorse wholeheartedly.

The National Stillbirth Society was founded in the months following Camille's stillbirth when we discovered the paucity of information available to women. In just 9 years it has grown to be the #1 source of stillbirth information in the world.

Michigan has an opportunity to supplement our educational efforts by enacting your legislation to bring medical professionals into the educational process. For a simple example of what women need to be told, we implore you to visit our companion website www.protectyourpregnancy.com. You'll be amazed!

Founder & National Director

During my second pregnancy, I was monitored much more closely, through both “high-tech” and “low-tech” methodologies. I underwent the more “high-tech” “non-stress test” bi-weekly in a perinatologist’s office and performed the “low-tech” method of counting kicks daily. I was taught how to count kicks in my second pregnancy. I was told that if I did not feel the appropriate number of kicks, to call the doctor immediately. (After this better monitoring, I gave birth to my second child, Mia Grace Thelin, in August 2009.)

What is important to know is that in my pregnancy with Katie, the day before the doctor told me that there was no heartbeat, I felt Katie slow down. She was surely not moving as she had been before that day. I had not been taught anything about counting kicks by my doctor. I had not been taught the importance of monitoring her movements or how to count the movements. While feeling concerned, I brushed it off, thinking that everyone says the baby slows down at the end because there is not enough room to move.

I had been taught about the signs of labor and was watching for those. “Call if your water breaks.” “Call if you experience contractions that get closer and closer together.” “Call if you see bright red blood.” I thought that if I had labor signs, I would call the doctor but did not want to disturb the doctor, on a Sunday no less, over my silly fears otherwise. Besides, I had an appointment scheduled for the next day (Monday) and an induction scheduled the day after that (Tuesday). Everything would certainly be fine. I was at the end of my pregnancy journey. She was so close to being born. I had experienced no problems in my pregnancy. Certainly everything was fine.

Everything was not fine. And my world would never be the same.

After my daughter was born on Tuesday, the doctor told me that she had been dead for only about 48 hours based on her appearance at birth.

I live with intense guilt and remorse over not calling. Perhaps I could have saved her life if I had done something differently. I just didn’t know. Although worried, I didn’t feel empowered to call.

With your important legislation, and the education and awareness of stillbirth that are so desperately needed, I believe children like Katie will be saved.

Please continue to work tirelessly to support this legislation. Do it for Katie and all the little children who lose their lives to stillbirth every year.

I would welcome the opportunity speak to you about this important topic in person. Feel free to contact me at the above-listed telephone number.

Thank you for your legislation and hard work to end stillbirth.

Very truly yours,

Tara J. Mooney

April 30, 2010

Representative Kevin Green

State of Michigan

Anderson House Office Building N 1096

Lansing, Michigan 48933

Dear Representative Green:

I am pleased to send this letter of support and appreciation to you for the leadership that you demonstrate in advancing legislation pertaining to stillbirth. Your efforts to author bills that urge national funding of research, and statewide education and awareness is greatly needed and appreciated.

As CEO of 1st Breath, a national organization dedicated to getting every viable baby to that first breath, we are working diligently with other organizations having similar goals to bring this issue to public attention and support. I personally did my dissertation on the need for First Candle to have a 24/7 hotline for parents and medical professionals dealing with stillbirth issues. There are actions that we feel may help reduce the number of stillbirths in our nation, but without public awareness and research too many of our babies will continue to die before they are able to take their first breath.

I urge the attention and support of your colleagues for House Bill 6091. It is necessary that health care providers notify soon-to-be parents, verbally and through written information, about the risk of stillbirth and preventative measures, especially kick counting. Please share this with your colleagues and put Michigan in the forefront of states that reduce the number of stillbirths.

Because every baby deserves a 1st Breath.

Dr. Pat Flynn, CEO

1st Breath

PO Box 28864

Kansas City, MO 64188-8864

816-830-9572

www.1stBreath.org

Honoring those born who never took a

Megan's Story

Hi! My name is Megan Heller. I wanted to share my success story with you. Last May I learned I was pregnant with my 3rd child. My doctor gave me a pamphlet about "Count the Kicks". I didn't remember getting anything like that with my first two pregnancies. When there were times where I felt like I wasn't feeling much movement, I would read through your brochure and follow the directions.

So, my 30th week came, and that weekend I started to feel less movement. The following Tuesday I felt nothing. I called and spoke with a nurse at my doctor's office. She told me to go home and drink something that was heavily caffeinated and to eat something with a lot of sugar, lie down, and focus on the baby for one hour. So, I did that and felt nothing. I called back, talked to my doctor this time and he told me to head to the hospital so they could monitor me. This did not make me feel better, and I thought, "Oh, I will probably feel it kick on the way and I am being silly."

At the hospital they monitored the baby's heart rate. After about 30 minutes I still felt nothing. The doctor thought the baby was moving but I assured him I still hadn't felt anything. Then they did an ultrasound and after an hour of scanning it was confirmed that our baby was not moving. The doctor said it looked like the cord was around baby's neck and that my fluid was low. He explained that the best thing was to deliver her now; even at 30 weeks she would do much better outside of me then inside.

So, I was rushed into surgery and delivered my sweet Abigail via c-section on Dec. 8th, 2009. She weighed 3.2 lbs. After delivery we learned that her cord was wrapped around her neck 3 times and had a knot in it. The doctor told me she probably would not have made it another hour. I was shocked! I am so thankful that I read your information (almost daily) and listened to my body. Abigail is truly a blessing, my little miracle!

I want to thank you for starting your organization and getting the information out there. I know it is not meant to scare people, but to inform them. This was my third pregnancy after two very healthy, easy pregnancies. I never thought anything would go wrong this time, but it did. So it goes to show that every pregnancy is different and that women need to be aware and listen to their bodies.

Megan Heller
Davenport, IA

Good evening, I saw the news piece regarding Count the Kicks and was immediately frozen. I gave birth to my daughter 2 years ago in April. I was in labor for 23 hours when I was not dilated or thinned they advised me they would need to take the baby c-section. It turned out that my pelvic bone (front to back) is tilted and too narrow to have children naturally. When my Isabelle was born they advised me she had a true knot in her umbilical cord and by some miracle I happen to be unable to birth children naturally or no doubt we would've been down the same tragic road. It scares me that this could possibly happen again to me or anyone I know and I will gladly pass on your campaign link. I wish I would've known this information during my pregnancy so I will use that to pass the info on.

Thank you so much for sharing your stories and saving many lives. Those babies are angels and will be angels for so many.

Thank you,
Carrie

I recently (Jan 15th 09) lost my son Kooper Allan James Lohoff one day prior to being induced. He was a healthy 7 lb 9 oz baby boy. His umbilical cord was nearly 7 ft long and had not 1 but 2 knots.. I had told my Dr. several times that something was wrong.. he didn't move like my other two children did... So she had me sent in for 3 ultrasounds all of which showed nothing to be wrong.... How they could miss a 7ft umbilical cord is beyond me ...

I would love to help in anyway possible to spread the word..

Thank you so much for what you are doing
Amy jo Lohoff
Creston Iowa

Just wanted to let you know how important your campaign is. Keep it up.

Losing a baby in stillbirth is a pain and loss that never goes away-----I also know from experience. **I was pregnant in 1977** with my first child and my due date was just a couple of weeks away, when I went in for my regular check-up and they couldn't find a heartbeat----then I was rushed in for ultrasound and given the devastating news about my baby (very clinically). I thought my baby's movement had become less, but at that time everyone said "oh, they always get very quiet shortly before birth"...not true, of course.

My husband and I couldn't believe it. They sent me home and I went into labor the next day----delivery was so, so sad. I was terrified---in my early 20's. This was back during a time when everyone wanted to *protect* the mother, so I didn't get to hold my little boy (doctor thought it would be too painful for me). My husband planned a small funeral, which I did not get to attend. I was still in the hospital, and everyone thought it would be too painful for me...

As with other babies, my little boy was perfect, except the cord was tied around his neck rather tightly. No other explanation could be determined.

It took me four years to get pregnant again (I was just so obsessed I think with having a baby), but GOOD NEWS, I did get pregnant again and my tears turned to joy. He was a gift---never taken for granted. I think about my first child every day and always will, but was so thankful to have a happy, healthy baby----oh, he is now 27!

Your efforts in this campaign are selfless. Thanks for letting me tell my story from a 1970's perspective.

Deb Hart

Hello,

wanted to send you a message after I saw you on the news this morning, that I am interested in helping in anything that you would need. I lost my daughter on 8/22/05. She was 36 weeks and I had a normal pregnancy. She was stillborn after I didn't feel her move. I learned later that I have a blood disorder and that was the cause of her death. I had a normal preg in 2002 and was able to have another baby in 2007. I am very blessed to have 2 healthy boys, which I know lots of Moms who never get to hold a healthy baby.

My concern is knowing the lack of movement of the baby but also for Mom/Dad who experiences this death. I really didn't have any resources to look to after her death. I had great support by my family and there was a lady in my town who was my age that had went through the same thing a few years earlier. I would like to see the hospital do more in helping with the death. I was wondering if your group has helped with over this past few years, support groups etc.

My life, like your life, has moved on but I think of my daughter every day and I would like to think that others feel the same way I do. Thank you for your time and thank you for getting the word out to others. Sarah Madsen

We heard about the spot on Ch. 8 last night. We lost our Brooklyn one month ago. Your stories sound just like ours. We are taking the Count the Kicks info to our OB dept Thursday. Hopefully they will get on board and at least give out brochures to expecting moms. We are struggling as you might guess. We don't know of any support groups near by focusing on stillbirth. Is there any? We are in Ottumwa. Our local hospital and doctors have not been very supportive. We feel they just want us to go away and let it go while we feel we want as many answers as possible for prevention and closure. Thank you for any help and keep up the good work. We feel like we should have been told and educated about counting the kicks. How hard is that? Not hard. Our situation may not have been helped by counting but others sure would so why not teach women to count. Makes sense to us.

Brent and Belinda Lindberg

My name is Christina Hanbeck and I live in Newton. I lost my daughter in 2007 from a double true knot in her umbilical cord. I was 38 weeks and went in for my weekly appt. They rushed me in for an emergency c-section because they couldn't find a heartbeat. When I woke up I had two ministers standing ove me. That was, without a doubt, the worst day of my life. The week before at my appt. the doctor said everything was awesome and she had a strong and steady heartbeat and that the ultrasound they did looked wonderful. I have two older daughters and I know from experience that the babies slow down during the last couple of weeks of pregnancy and so I didn't think anything of it when she wasn't moving around as much. I am so happy you have started this campaign to help other mothers to save their babies. I have been wanting to get involved with an organization like this that was close to home. If there is anything that I could help with please let me know.

Sincerely,

Christina Hanbeck

Proud mommy of an angel baby

I do have to work Thursday night and so I will not be able to make it to the kick off event but please put Caitlin's birthday on the calender.
Caitlin Grace Hanbeck April 5, 2007.

Also, I would love to be part of the network.

Christina Hanbeck

509 East 14th Street North Newton, Iowa 50208

541-275-1300

Caitlin Grace Hanbeck

I would also be honored if you used my email on the new web page or any other

awareness that cord issues are not the only cause of stillbirth. What my daughters suffered was a sort of slow starvation.

Counting the kicks is a great way to make women aware of so many things, making them more aware of their own bodies- as well as the one growing within it. I applaud you for having the courage to make a difference. What an important mission.

Thank you!!!!!!

Kari Madole

Hi Kate-

I hope the kick-off event went well, my apologies I was unable to attend.

I would be honored to be a part of your Parent to Parent network. We are nearing the 7 year mark since we lost Ella, so I am not sure that we still fit your qualifications- but I am willing if you need me! I would be honored as well to be a part of your website if you have a place for our story. All of them are important and the more people read, the more educated they will become.

Ironically, I have just found out that I am expecting again. This will be my 4th pregnancy, I have 2 beautiful girls at home, and never expected to be in this situation again... surprise!!! We are only dealt the cards we can handle, right?!! Anyway- I will be using my kick chart and paying close attention with this one- I'm not a spring chicken anymore!!

You may contact me via email anytime, though I only work part-time and may take a few days to respond. Thank you again!!!

Kari Madole

Wow, I am not even sure where to start. I am currently home on maternity leave after losing my second baby in seven months. My first loss was a son Edric William. I was 37 weeks pregnant. Everything was going along fine. I had just been to the doctor the day before and had a normal non-stress test. That night my husband and I lay in bed feeling Edric move all over the place. I felt him move the next morning when my husband got up for work and then I got up and went about my day. Mid morning after making my nesting list of to do items I realized he hadn't moved much in the past couple of hours. I went up and lay down on the bed to count kicks and there was maybe one (or that may have been wishful thinking) over the next hour. I called my doctors office and they told me to come right in. I never dreamed I was going to find out my son was gone. When both the nurse and the doctor couldn't find any heart tones we went into an ultrasound room and it was confirmed that he was gone. I was devastated and in shock. I had to call my husband at work with the news. This was my husband's first child. (I have a healthy 11 year old son and 9 year old daughter from a previous marriage.) After I delivered there was a large tight knot noted in the cord. Edric was a perfect baby in every way. I can't even begin to tell you what we went through over the next few days and weeks. I am sure you already know. I became obsessed with trying again and the minute we had the green light from the doctor I was on a mission. I knew it wouldn't replace Edric but I had to try again. I was lucky enough to get pregnant again in 10 weeks. I was very nervous and afraid sometimes but my doctor and her staff were great. Everything seemed to be going well. I went in for my regular check up on May 4th (I was 19 ½ weeks) and found there was no heart beat. I had just been in a week before and had a quick ultrasound verifying heartbeat and lots of movement. I delivered Noah Alan 4 days later. By all appearances he looked normal yet incredibly small. As of today it doesn't look

like we are going to get any answers as to why he died. I am angry and numb. We were just coming to grips with losing Edric and now Noah too. What are the odds?!

My friend emailed me last night after seeing your story on the news. I just watched it. I would do anything to keep someone else from going through this unspeakable pain. I would love to visit with someone and help with your campaign in any way that I can.

Sincerely,

Christine Greaves

(C) 515-710-9917

I applaud you in your efforts to get this information out to people. My son, who is now a happy and rambunctious 16 month old, was born via emergent c-section after I couldn't feel him moving.

I'm glad that I trusted my instincts and went to the doctor when I did. I'd had an odd feeling all day, and worried because I hadn't felt the baby moving like usual. Several women told me that less movement is normal and happens shortly before delivery because the baby is so low. Luckily I listened to a toddler's diagnosis while he played doctor. Seriously. I'd been on bedrest for preterm labor for four weeks. On Feb 7th, the first day of week 37 of the pregnancy, my doctor told me that I could start picking oldest son, Aiden, up from daycare in the afternoons and spending some quality quiet time with him after bed rest in the mornings. Aiden was supposed to be napping, but wouldn't. He wanted to play with his doctor's kit, and always liked to use his stethoscope to listen to the baby. He would usually jibber jabber while he checked my belly, but that day he was quiet. As we always would ask him when he played doctor, I asked "How is the baby, doctor? Is he good? Is he OK?" Instead of smiling and nodding like usual, he told me "No, Mommy." I started crying and told him that I didn't think the baby was ok either. I put him in the car and we left for the hospital. I didn't call ahead; I didn't follow the rules and call the clinic ahead of time - I just went straight to the labor and delivery floor at the hospital. The nurses and doctors acted quickly, and Preston Lee was born shortly after I arrived.

His "birthday party", as the nurses in the NICU called it, was not an enjoyable one. Doctors started CPR immediately because Preston was not breathing and his heart was not beating. After several minutes, his heart rate picked up and he began making breathing efforts. Several times during our stay in the NICU, nurses would gather in his room to hear me tell the story about Aiden playing doctor. All the things that I had just thought of as Preston's birth story have become stories about blessing after blessing that we've received. I'm so amazed at how fortunate we are, and the medical professionals tell us over and over how fortunate and how lucky we are that things turned out the way they did.

Despite his rough start, and his already thick folder of medical records, Preston has done so well. Preston has overcome all of the problems that were discovered in his organs (stomach, liver, kidneys, bone marrow). A CT scan and MRI confirmed that Preston had suffered a Grade IV. Whatever caused him to be in such distress is what caused the other organ problems. His reactions to that distress caused meconium stain, which caused pneumonia. The doctor explained that his body knew to sacrifice the health of some of his organs in order to best preserve his brain. If that had not happened, the damages to the brain would have been much worse. He is a big boy, and is very strong - in more ways than one! He is such a fighter, and at only a few hours old I already admired him for his incredible strength and determination. He could have given up before he even got started, and I feel so fortunate that the health professionals and I acted when we did.

I would love to help you with this campaign. My sister-in-law, Missy Winterboer, e-mailed this link in mid-May. I looked at it then, and saved the e-mail because I planned to write to you and thank you for creating this organization. I got busy, and never wrote...you know how that goes... I found out today that some friends lost a child in the 8th month of the pregnancy. They went in for a regular check-up, but there was no heart beat. An ultrasound confirmed that the baby had died. More people need to know about counting kicks! I didn't know about it, even though it's the reason I'd

gone in. I was just lucky. If there is anything that I can do to help you with this, please please let me know. I would be more than willing to help.

Amanda Brezina

Dear Representative Marc Corriveau and Members of the House Health Policy Committee,

On Sunday, I celebrated my third Mother's Day by placing a carefully arranged pot of flowers at the graveside of my daughter, Annika. It is a tradition I would not miss. My daughter, Annika Beth Heeringa was stillborn on July 9, 2007. She was 36 gestational weeks old, six pounds, 20 inches long, had lots of dark hair, big feet, and was perfectly formed. Each day Annika is loved, remembered, and missed in our family. After a full autopsy of Annika and a complete medical work-up of myself and my husband, Annika's death was ruled a case of Sudden Antenatal Death Syndrome or SADS. You might never have heard of SADS, I hadn't, until faced with it the most personal, painful and life-changing way.

Sudden Antenatal Death Syndrome claims thousands of lives each year and takes ten times as many of our children as does its more well-known counter-part, Sudden Infant Death Syndrome or SIDS. SADS is equally devastating. My daughter was less than a month from her due date. Her bedroom was complete, her diapers were stacked in cupboards, and her clothing was washed and placed in drawers. From the moment I could feel my baby move inside of me, I was attached and invested in her life. When my husband and I learned that Annika had died in-utero, we were shocked. We simply did not know this could happen. I had the perfect pregnancy, got regular pre-natal care, ate well, gained the appropriate amount of weight, and felt great throughout my pregnancy. During my pregnancy, I was never educated about Sudden Antenatal Death, Stillbirth, kick-counts, or how to monitor my child's well-being by being aware of the number, type, and quality of her movements. I was never informed that by paying specific attention to my child's activity at the same time each day, I could help monitor her state of health. In fact, three days before Annika's death, I noticed a change in number, type and intensity of her movements. I had no idea that this could be a sign of distress in my daughter. After all, I had just been to the obstetric office and everything was supposedly fine. I was not concerned when perhaps I should have been. When changed movement become no movement at all, I did seek care. It was too late. My daughter was gone, my emotional pain was intense, and I was in a complete state of shock. After the doctors confirmed Annika's death, I felt so very alone. I felt as if I had been a victim of the rarest of complications. I had heard of SIDS but SADS, stillbirth... I simply did not know that this happened in the United States of America, in 2007, to healthy patients with regular doctor's care. In the months and years following Annika's death to Sudden Antenatal Death Syndrome, I have met countless parents who have lost infants due to SADS and stillbirth. In fact, I have learned that this type of death is not rare at all. It kills 1 in every 116 babies...babies who, like my daughter, were fully formed and ready to come home.

It is time that SADS gets the attention it deserves. It is time pregnant woman are informed by their health providers that problems can occur late in pregnancy, and that these problems can be fatal. It is time women are told that there is something they can do to monitor their baby's health, and its easy and its free. It is time Sudden Antenatal Death Syndrome is brought into the public eye just as Sudden Infant Death Syndrome was years ago. It is time that pregnant women are empowered to protect their children through education on SADS, stillbirth, and kick counts.

I urge you now to help us makes SADS and stillbirth a topic that obstetric health care providers talk about with their patients. Help us educate new mothers about kick counts and specific awareness of their baby's movement. Help us save lives just as the "Back to Sleep" campaign has saved babies from SIDS. Help pass House Bill 6091.

Sincerely,
Alison Heeringa